Advance Care Planning: Past and Future

Jeffrey B. Rubins, MD
Director, Palliative Medicine
Hennepin County Medical Center
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Disclosures: Content advisor to Lumināt, developing Advance Care Planning solutions
Advance Care Planning

- Essential to ensure patients get the care that they want
- Efforts to implement have not been successful
Reasons Why Advance Directives "Fail"
1. Not done
1. Not done

- Average Completion rate 29%\(^1\)
  - Ages 35 – 49: 24%
  - Ages 50 – 59: 39%
  - Ages > 60: 51%

- Completion rate in NH residents = 36.4%\(^2\)

2. Forms/decisions not understandable
   • 41% of adults in one study selected options on form inconsistently\(^1\)

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3. Not applicable to medical decisions
   • SUPPORT project
     • 569 (14%) of 4804 patient charts with AD
     • 36 (0.7%) of 4804 address life-sustaining treatments in present medical situation

4. Focus on treatments, not values/wishes
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“...an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments”

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Minimum Acceptable Quality of Life Outcome (MAQLO)
5. Not discussed with agent
   - Systematic review: Healthcare Agent accuracy 68% (based on responses to hypothetical situations)

6. Not available when needed
   - 26% of medical charts had accurate information about AD
   - 16% of medical charts had AD form

Morrison, R.S., et al. The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings. *JAMA* 1995;274:478–82
7. Not followed by provider
   • Providers considered prognosis, perceived quality of life, and wishes of family or friends over advance directive

Advance Care Planning: Origins as Legal Transaction
Phase 1. Living Will

- 1967 Euthanasia Society of America
  - Common law and Constitutional law premise
    - “The law provides that a patient may not be subjected to treatment without his consent”
  - Individuals should indicate in writing in advance the extent to which they would consent to treatment

1960s and 1970s advances in medical technology
- Low pressure cuff endotracheal tube for positive pressure ventilation
- DC external defibrillation
- CPR
- Medical ICUs

Became difficult to distinguish saving life from prolonging death

1975: Karen Quinlan took an overdose and arrested at age 21
After 4 mos, parents wanted her removed from the ventilator - Karen was quoted as saying that she never wanted to be kept alive by extraordinary means
NJ Superior Court allowed the removal of her ET tube in 1976
Consequences

- Legal model of living will
  - focused on legal formalities intended to protect vulnerable populations (with diminished capacity) from harm
- But these applied to narrow range of treatment decisions to which laws applied

Sabatino CP. The Milbank Quarterly. 2010; 88:211–239
Phase 1. Living Will (1970s)
Phase 2. Power of attorney for healthcare (1980s)
Phase 3. Out-of-hospital DNR orders (1990s)
Phase 4. Default surrogate or family consent laws

Phase 5: Advance Directive for Health Care

- 1990 Patient Self-Determination Act
  - Part of Omnibus Budget Reconciliation Act
  - Addendum to Medicare/Medicaid law
- Requirements
  - Provide written information
  - Maintain written policies and procedures
  - Document whether patient has AD
  - Educate staff and community
Phase 5: Advance Directive for Health Care

- 1990 Patient Self-Determination Act
- 2007 Congress added “end-of-life planning” to initial preventive physical examination available to new Medicare/Medicaid enrollees
- 2009 Congress proposes Medicare coverage of voluntary advance care planning consultations
Palin, Aug. 7, 2009: The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s “death panel” so his bureaucrats can decide, based on a subjective judgment of their “level of productivity in society,” whether they are worthy of health care.
Consequence:

- Conventional advance directives have relatively little impact on end-of-life decision-making.
Advance Care Planning: Moving from Legalistic to Communications Approach
Focus on discussion with family (and physicians) rather than completing legal document

Recognition of oral directives and designation of agent documented in medical chart

Iterative process

Self-help tools
  - Planning
  - Values and wishes
  - Discussion
Advance Care Planning: Moving to Communications Approach

WHAT IS HONORING CHOICES?

WATCH THIS VIDEO TO FIND OUT MORE

CLICK HERE

Honoring Choices Minnesota hopes to inspire and support many community-based conversations regarding end-of-life care planning. We urge Minnesotans seeking to start such conversations in their family, faith, cultural or community group to use this "toolkit" of video, text and web-links to support these conversations.

FAMILY STORIES
Everyone has a story. These video clips will inspire and educate on how to begin thoughtful health care conversations with your loved ones...

HOW TO BEGIN A CONVERSATION
Should you begin the conversation on a birthday, an anniversary, or a rainy Monday? In these video clips...

Get Involved!
Click here here to learn more

Featured Video
Doctor's Blueprint
He explains how a directive slide doctors and distant family members.

We're in the news!
StarTribune
Advance Care Planning: Past and Future
Using technology to improve Planning, Values, Discussion

- Web-based programs to improve provider skills

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**INTRODUCTION: DEATH AND DYING TODAY**

Most Americans have fears and concerns about the "dying" and "death" processes. People fear experiencing pain and unrelieved symptoms; they worry that when "nothing more can be done," their healthcare providers will abandon them; and they are concerned that their family will lose all their savings paying for life-sustaining technology and invasive, debilitating treatments.

Despite the fact that many medical and technological advances have been made over the past century, people are dying in institutions with strangers caring for them, as they suffer from prolonged, chronic illnesses, and in many cases, receiving expensive, futile treatments that pose an enormous financial burden to their family. Most Americans (70%) would prefer to die in their own homes, yet only half of all deaths occur in hospitals and...
Web-based programs to improve provider skills
Using technology to improve Planning, Values, Discussion

- Web-based programs to facilitate discussion
Using technology to improve Planning, Values, Discussion

- Web-based programs to facilitate discussion

Welcome to PREPARE!

PREPARE is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

Click here if you are new to PREPARE

Or, click here if you have used PREPARE before

Click an answer above to move on.
Using technology to improve Planning, Values, Discussion

- Web-based programs to facilitate discussion
Using technology to improve Planning, Values, Discussion

- Web-based approach to Advance Directives

**Five Wishes**

Five Wishes lets your family and doctors know:
- Who you want to make health care decisions for you when you can’t make them.
- The kind of medical treatment you want or don’t want.
- How comfortable you want to be.
- How you want people to treat you.
- What you want your loved ones to know.

Five Wishes is changing the way America talks about and plans for care at the end of life. More than 18 million copies of Five Wishes are in circulation across the nation, distributed by more than 35,000 organizations. Five Wishes meets the legal requirements in 42 states and is useful in all 50.

Five Wishes has become America’s most popular living will because it is written in everyday language and helps start and structure important conversations about care in times of serious illness.

Five Wishes was introduced in 1997 and originally distributed with support from a grant by The Robert Wood

[Image of Aging with Dignity website]

[Image of Five Wishes book]

[Image of Five Wishes brochure]
Using technology to improve Planning, Values, Discussion

- Web-based approach to Advance Directives
Using technology to improve Planning, Values, Discussion

- Web-based approach to Advance Directives
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Potential of Online Advance Care Planning

- Increased completion
  - “Meets the patient where they are”
- Accessible 24/7 in variety of locations
- Serves needs of diverse population
- Addresses different needs for healthy, chronically ill, and terminally ill
Potential of Online Advance Care Planning

- More understandable and applicable
- Provides consistent educational content, includes interactivity and video
- Explores wishes from perspective of medical decisions

Feeding Tubes

Decision Making
Exploring decisions about feeding tubes.
Potential of Online Advance Care Planning

- Not discussed with agent (and provider)
- Not current
- Not available when needed

- Stored in a secure “cloud” database available to patients and their providers at all times
  - Clinic visits
  - ED
  - Hospital
- Ability to notify agents (and providers) regarding completion and updates
- Easily updated as part of routine care
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Email: rubin004@umn.edu